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Charles M. Balch, MD

February 14, 2002

The Honorable **Jo Anne Barnhart**  
Commissioner of Social Security  
P.O. Box 17703  
Baltimore, MD 21235-7703

**Re: 20 CFR Part 404, 66 Fed. Reg. 59306 (Nov. 27, 2001)**  
**Proposed Rules Regarding Revised Medical Criteria for Evaluating**  
**Hematological Disorders and Malignant Neoplastic Diseases**

Dear Commissioner **Barnhart**:

The American Society of Clinical Oncology (**ASCO**), an organization representing over 17,000 physicians worldwide **who** are engaged in cancer treatment and research, **submits** these comments in response to the proposed **rule issued by the Social Security Administration (SSA)** that revises the medical criteria for evaluating hematological disorders and malignant neoplastic diseases **for** purposes of disability determinations.

**ASCO** members are **typically** involved in the diagnosis, evaluation, treatment, and **cure of** malignant neoplastic disease. **By** submitting these comments, the organization seeks to provide additional professional insight that may be helpful in the formulation of medical criteria **for** evaluating patients with hematological and malignant neoplastic **cancers**. We **are pleased** that the **SSA** continues to attempt to modernize and update the disability eligibility criteria **for** individuals whose lives have been impaired **by** malignant neoplastic disease, and **we find the** proposed rules generally to be comprehensive. We do, however, offer the following comments:

First, **ASCO** disagrees with **SSA's** assessment that the current listing for bilateral retinoblastoma (113.05A) should be deleted based **on** advances in treatment. **Most** children with **this** disease are unilaterally blind and have decreased vision in their second eye, **resulting in significant** visual impairments. **We** believe **that** advances in treatment do not justify **a** change in **SSA's** view **of** the condition with **regard to** disability determinations.

Second, with regard to malignant neoplastic diseases treated by allogeneic bone **marrow or** stem cell transplantation (113.28), we believe **that** the 12-month disability timeline is too short, especially for children. **SSA should** allocate

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**additional months** to the timeline, considering the increased **risk of** acute **or** chronic *graft vs. host* disease **and infection** in pediatric patients.

**Third**, we disagree **with SSA's** determination that recurrence of Hodgkin's disease more **than** 12 months after the completion of **initial** antineoplastic therapy automatically constitutes a new **disease** rather **than** a recurrence (13.00K(1)(c)). Oncologists **recognize two** different patterns of relapse that can **be** associated with **Hodgkin's** disease. One **pattern involves the** presence of residual **masses** in patients that have undergone therapy for the disease. **In these** cases, it **is** uncertain whether the residual mass indicates remaining disease **or simply benign** post-therapy fibrotic tissue. **If the mass starts** to grow again, **then the mass likely** constitutes **residual disease**. Other patients **may** develop **new areas of** disease **or** regrow **nodes that had** completely disappeared. **Oncologists still** consider such patients **as** having relapsed, rather **than** having developed **a new** disease.

Fourth, **SSA's** criteria **for evaluating leukemia (13.00K(2))** fail to include the **initial** diagnosis **and** relapse **of** granulocytic sarcomas. We believe **that SSA should** include a **specific listing** for patients **with this** condition.

**Finally, as a general comment**, **ASCO** stresses **the importance of focusing on an individual's** particular situation, **especially when he or she incurs** significant limitations **past the** listed disability time period. **Cancer** patients typically incur **short-term impairments resulting from** toxicities associated with chemotherapy **and** other treatment, **and from the disease itself**. **SSA should, however, be** mindful **that** impairments from treatment (e.g., **cardiotoxicity and** infertility) **can manifest several** years later, **and that** a tumor may cause disability **to a patient for a period of** time **far surpassing** that which **has been** allocated **by** the proposed regulations for certain **malignant neoplastic diseases**. We believe **that it is essential that** the new regulations maintain **sufficient flexibility to** adequately **adjust disability time periods based on the individualized** nature **of cancer and patient** responses **to treatment of** the disease.

**ASCO** appreciates the **opportunity** to offer **these** comments **and urges SSA** to consider **them** in formulating its final rule.

Respectfully submitted,

A handwritten signature in black ink that reads "Deborah Y. Kamin". The signature is written in a cursive, flowing style.

Deborah Y. Kamin, Ph.D.  
Senior Director, Public Policy and Practice  
Department